

Northumbria Research Link

Citation: McInnes, Alison (2022) Navigating the choppy waters to Nirvana: A critical reflective account of caring for ageing parents in the fourth age. *Ageing & Society*, 42 (10). pp. 2227-2243. ISSN 0144-686X

Published by: Cambridge University Press

URL: <https://doi.org/10.1017/S0144686X20001956>
<<https://doi.org/10.1017/S0144686X20001956>>

This version was downloaded from Northumbria Research Link:
<https://nrl.northumbria.ac.uk/id/eprint/45642/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)



**Northumbria
University**
NEWCASTLE



UniversityLibrary

Navigating the choppy waters to Nirvana: A critical reflective account of caring for ageing parents in the fourth age

Alison McInnes¹ 

¹Department of Social Work, Education and Community Wellbeing, Faculty of Health and Life Sciences, Northumbria University, Newcastle upon Tyne, UK
Email: alison.mcinnes@northumbria.ac.uk

(Accepted 15 December 2020)

Abstract

This article revisits a paper and from an autoethnographic/critical reflective biographical approach re-examines seven cultural notions or myths, which may encourage ageism. It is framed within my experiential knowledge of caring for my ageing parents, with the tensions and challenges around problematising the value of expertise based on experience, communication, grief, and autonomy and freedom *versus* safety. The commentary emphasises that by analysing the impact of our personal life experiences, we can start to understand both the intended and unintended consequences of policy and practice affecting those in the fourth age. As a social work educator, I wanted to reflect upon how my tacit experiential knowledge, if made explicit, could impact upon my own and others' learning. The recent death of my father has allowed for a period of reflection on my own caring and indeed my professional social work experience, knowledge, skills and practice. It is argued that the ageing process is unequal as class and socio-economic factors, *i.e.* geography, age, gender, religion and ethnicity, all play parts in determining how someone ages, and indeed upon the care an individual older person receives. A fuller understanding of negotiating the role of one stakeholder, that of a family carer in the ageing process, is elicited in this paper.

Keywords: ageing; critical reflection; expert by experience; fourth age; gerontology; personal experience; social work; autoethnography

Introduction

The paper proffers an autoethnographical/critical reflective biographical account from a registered social worker/educator in the United Kingdom (UK) re-examining seven cultural notions, or myths, which may encourage ageism (Dixon and Gregory, 1987; Sidell, 1995; McInnes, 2004). This commentary is based on the last five years during which I have (in collaboration with others)

informally cared for my ageing parents. Tensions and challenges that arose, and lessons learned, during this period will be considered in terms of the personalities of my parents and their physical and mental health. These will be examined in the context of the myths of chronology, inflexible personality, misery, rejection and isolation, dependence and unproductivity, physical ill health and mental deterioration (McInnes, 2004).

Demographics and context

The UK has an ageing population (Office for National Statistics, 2018) with approximately 12 million people aged 65 and above, of whom 1.6 million are aged over 85 years. Between 2017 and 2040, the number of people aged over 85 is projected to almost double from 1.4 to 2.7 million (Age UK, 2019). The older population is not a homogeneous group, but clearly some older people encounter certain difficulties in relation to their advancing years. Certain situations or problems are seen more frequently in the older population and ageism is a form of prejudice used by those who generalise the differences they observe to the entire older population (Chiu *et al.*, 2001; Levy, 2001). This approach includes viewing all older people as marginalised, vulnerable, frail and likely to be sick (Bytheway, 1994). The reality, however, is quite different (McInnes, 2004). Language and dominant discourses associated with the fourth age in policies and the media are often underpinned by ageism and fail to convey accurate accounts and understandings of successful ageing (Duffy, 2017).

There is a need, therefore, to understand ‘meaning’ when working with and researching older people, which requires distancing oneself from ageist preoccupations with the ‘decline of the body’ (Minkler, 1996). Indeed Hepworth argues that

ageing ... is not a straightforward linear trajectory towards inevitable physical, personal and social decline but a dynamic process of highly variable change: ageing is simultaneously a collective human condition and an individualised subjective experience. (Hepworth, 2000: 1)

According to Bytheway (1994, 2005), ageist prejudice is based upon presumptions about different generations or chronological age.

The term the ‘oldest old’ (people at the upper segment of the age pyramid, *i.e.* those aged 85 years and older) is stereotypically associated with a loss of autonomy and degeneration. In reality, a large proportion of older people will never lose their autonomy or suffer physical or mental ill health; it is unexceptional in many countries in the 21st century to reach this age and beyond. The ‘fourth age’, with its recognition of successful ageing (Rowe and Kahn, 1997), is preferred. However, this concept has been critiqued (Calasanti, 2016), in that it can overemphasise the positive aspects of ageing. Calasanti (2016) argues that not all older people have the power, resources, choices, networks, forethought or good luck to avoid ‘frailty’, and there is a need to avoid apportioning responsibility when acknowledging that some older people are at risk of ‘unsuccessful’ ageing.

Experiences of health care

Ageist and pejorative terms, such as ‘social admission’, ‘bed blockers’ and ‘frequent fliers’, habitually used in hospitals to describe older patients (Borland, 2011),

downplay the serious medical issues that some older people may have (Borland, 2011; Curran and Chattopadhyay, 2015), with physical and mental health problems interacting (Naylor *et al.*, 2016) and impacting on health and social care services (Davidson *et al.*, 2013). Such vocabularies are also a function of broader political choices and policies within neoliberal regimes around inadequate funding of our public services (Latimer, 2018). Furthermore, decisions are encoded, and priorities set within these policies, for the consequent distribution of resources underpinning the organisation and delivery of health and social care in the UK. For example, 'social admissions' and 'bed blocking' arise in a situation where there is insufficient care available within community and hospital settings (Manzano-Santaella, 2010).

Experiences of caring

Care for those in the fourth age is often provided by family, friends, neighbours, or a combination, without payment (unpaid or informal care), and may include emotional support, personal care and help with practical tasks (Kelly and Kenny, 2018). One in six adults (approximately 8.8 million people) are informal care-givers (Carersweek.org, 2019). Recent estimates of the number of unpaid carers in England suggest an increase from 5.9 million in 2001 to 7.6 million in 2018 (Petrie and Kirkup, 2018). Demos (2018) estimates the figure to be around 8 million, which will increase (Pickard, 2015), though carers' invisibility challenges the collection of reliable figures (Buckner and Yeandle, 2015). Tronto (2017: 30) identifies that informal family care is an expectation arising from neoliberal societies believing 'if people are now less well cared for, it must, by definition, be a failure of their own personal or familial responsibility'.

Policy analysts in the UK note inherent tensions between expectations to do more to support older relatives and pressures to stay longer in employment (Starr and Szebehely, 2017). Providing unpaid care can have adverse effects on carers' relationships, finances, health and wellbeing, and ability to participate in employment (Kelly and Kenny, 2018). Carers juggle their caring and paid employment roles, often foregoing career development opportunities and taking annual or sick leave to provide care (Carers UK and Age UK, 2016). In addition, a deprioritising of the carer's health, diet and exercise routine is common (Pinquart and Sörensen, 2007; Bauer and Soua-Poza, 2015).

There are also tensions between recognising gendered experiences of providing care and the experiences of older people receiving care (McKie *et al.*, 2002). When older peoples' experiences are considered in research, this is often in terms of the burden that this presents to younger female carers (Calasanti, 2006). Older women and men, as providers or receivers of care, often remain invisible (Calasanti, 2006). Linked to the gendered experiences of receiving care, Twigg (2004) draws out the relevance of theorising about the body for those in the fourth age, arguing that ageing bodies (and especially ageing womens' bodies) often become invisible in our society. This is juxtaposed with the emphasis on the body dominating subjective experience, to the extent that it engulfs all other factors, *e.g.* relationships, morale or individual preferences relating to the carer's gender. Moreover, Rummery and Fine (2012) argue that care from individualistic and paternalistic paradigms in research and society often disempower those who give and receive care, and any choice in the matter is absent.

For many older people and their families, getting access to, co-ordinating and maintaining decent quality, stable and reliable home care is a real struggle (Pursch and Isden, 2018). The lack of continuity of well-trained formal carers can be distressing, with new care workers being sent on a regular basis (Age UK, 2018). Older people and their families sometimes find the process for accessing help poorly signposted and hard to navigate. There have been reports of over-worked care workers not staying the full length of their planned visit and 'box ticking' by multiple different care workers each week, with consistency of care workers often not given priority by service providers (Stockwell-Smith *et al.*, 2010; Age UK, 2018; Pursch and Isden, 2018). The result can be insufficient time to construct relationships and poor communication.

This is often compounded by older people declining offers to see their general practitioner, or refusing support services at home, a phenomenon described as 'resistance to care' (Konno *et al.*, 2012). The language of 'resistance' is quite common and includes 'rejection of care', 'lacking insight', 'aggressive behaviour', 'combative behaviour', 'agitated behaviour' and 'non-compliance' (Konno *et al.*, 2012). A critical, gerontological response to this language argues that responses by an older person may be because services are unresponsive or irrelevant to them. For older people, the changes and transitions and the emotional impact involved in using care services (e.g. being observed naked in the shower) may require significant adjustment, acceptance and mutual understanding from both those providing and receiving care. These dilemmas around caring will be explored from an auto-ethnographic perspective.

Methods

Following in the footsteps of Ernest Hemingway (1964) to 'write what you know', an analysis of my own personal journey of caring for my ageing parents is explored to make my tacit experiential knowledge explicit and so enrich, validate and authenticate a fuller understanding of the ageing process. The pervasive language espoused in dominant public discourses in the UK regarding the alleged burden of older people is often alarmist and diminishes the value and integrity of being an older person (Calhoun *et al.*, 2012). For example, Willetts (2019) explores the intergenerational attitudinal gap in his provocatively titled *The Pinch: How the Baby Boomers Stole Their Children's Future – and How They Can Give It Back*. Analysing cultural notions, or myths, about ageing will underpin a challenge to the use of ageist language, discourse and communication styles when working with people in the fourth age.

This article draws on autoethnography as a form of qualitative research in which I used critical self-reflection to explore my anecdotal and personal experiences of caring for my parents and connected my autobiographical story to wider cultural, political and social meanings and understandings of ageing. Ellis (2004: xix) defines it as 'research, writing, story, and method that connect the autobiographical and personal to the cultural, social, and political'. As a method, it is about understanding the relationship between the self and others (Chang, 2008), to oppose 'otherness' (Richards, 2008). This is achieved by confronting dominant forms of representation and power to reclaim, through self-reflection, representational spaces

that marginalise certain individuals and groups (Tierney, 1998). Autoethnography, with its strong emphasis on self, has been criticised as a research method, as being subjective, self-indulgent, narcissistic, introspective and individualised (Doloriort and Sambrook, 2009). Therefore, reflexivity is important to counterbalance the above.

Adams *et al.* (2015) argue reflexivity includes both acknowledging and critiquing our place and privilege in society, and using the stories we tell to break long-held silences on power, relationships, cultural taboos, and forgotten and/or suppressed experiences. According to White (2001: 102), 'reflexivity becomes a process of looking inward and outward, to the social and cultural artefacts and forms of thought which saturate our practices'. Reflexivity suggests that by analysing the impact of our personal life experiences of caring/relationships with parents (Sakellariou, 2015), we can start to understand the intended and unintended consequences of policy and practice, in this case affecting those in the fourth age.

Context and expertise based on experience

Although the context of this paper is UK-based, many of the themes identified have relevance internationally. Ageing is a global phenomenon, though its trajectory and the response to it is not. I have become 'an expert by experience'. This term has been adopted in UK social care (Commission for Social Care Inspection, 2009) and social work education (Department of Health, 2002; Preston-Shoot, 2007) to value the lived expertise of contributors. These include people living with or caring for a person who uses services (Scourfield, 2010).

McLaughlin (2009) critiques this term by asking what criteria are used to define an 'expert' and their 'experience', and questions the unequal power position between a social worker (by virtue of their training) and an individual receiving services (McLaughlin, 2009). Further criticisms include a lack of diversity of contributors and an over-emphasis on negative experiences (Anghel and Ramon, 2009). It has been contested, however, that 'experience should be prominent in the conceptual base of gerontology' (Bytheway, 1996: 613). My 'expertise by experience' claims no universality, as I am not an expert on everybody's experience of caring for ageing parents. Ageing is unequal, as class and socio-economic factors, *i.e.* geography, culture, age, gender, religion and ethnicity, all play parts in how someone ages and indeed upon the care an individual older person receives (Higgs and Gilleard, 2020).

This commentary also draws attention to my social work educator role by examining possible relationships between my professional practices and my personal experiences emanating from my family of origin (Smith, 2012). Social workers should not only be concerned with utilising formal knowledge, but also encouraged to examine personal knowledge critically and reflectively (Kwan and Reupert, 2019). The self plays a critical role in how to 'frame an ambiguously troublesome situation [and] impose a narrative structure through which the incoherent features of that situation are named and storied' (Sellick *et al.*, 2002: 494).

Therefore, my own social location also needs to be acknowledged. As females, we are stereotypically credited with being innately caring and may be expected to take on the bulk of the caring tasks (Lewis, 2002). This fortunately was not my

experience, with my brother and I sharing the emotional support, some personal care and all the practical, housing, legal and financial tasks/decisions for our parents. This continues on a daily basis. As a daughter and a professional I do, however, have competing demands on my time. For example, I found it increasingly difficult to accompany my parents on their many routine hospital visits. Geographic distance and time shortage were and are constant pressures on my caring role. Moreover, in analysing the caring relationships with my parents, I also need to consider that my personal needs may have 'leaked out' in unforeseen ways (Kwan and Reupert, 2019), via the phenomenon known as 'transference' (Smith, 2012; Butler, 2018).

By using critical reflection, the power relations, interactions and the decisions made between me, my brother and my parents are explored (Hakaka and Holmes, 2017). Reflections were manifested through writing in a journal (Hickson, 2011). Boyd and Fales (as cited in Lam *et al.*, 2007) distinguish stages of reflective learning, which includes inner discomfort. At the beginning of my journey in caring for my parents, I experienced inner discomfort at the nature of the personal experiences I brought to my social work educator role. This included contemplating what others might think of these experiences and how I would integrate these positively with benefits to my own learning and practice (Smith, 2012).

Tensions and contradictions exist between critical reflection and the cultures of objectivity and self-disclosure. The personal and the emotional in learning has been explored by Fook and Askeland (2007), using their model of Critical Reflection. Critical Reflection can involve personal disclosure and acknowledging emotion, which may compete with the social work educator experience of being rational and objective (Fook and Askeland, 2007). I needed to be mindful and utilise critical social work to examine inequality and oppression, and be aware that notwithstanding its intentions to provide help to older people, social work practice itself might be oppressive and socially controlling (Healy, 2012; Smith, 2012).

The product of my critical reflective analysis of the impact of my personal life experiences is applied to seven cultural notions, or myths (Dixon and Gregory, 1987; Sidell, 1995). It was argued that these myths exist with some basis in truth and fact (McInnes, 2004). However, they have become exaggerated and generalised, leading to stereotyping which can in turn promote oppressive practice. These stereotypes, or established lay or cultural beliefs, are maintained because there are elements of truth in them, but generally they over-simplify and stigmatise (McInnes, 2004). The following list of myths was utilised as an important safeguard, or check against prejudice, negativity, discrimination, inequality, oppression and misunderstanding of my parents' lives.

The myth of chronology

The myth of chronology defines older people as a homogeneous group by virtue of their age, despite the diversity and autonomy in their lives. Several key points have emerged which all informal carers and professionals making decisions about those in the fourth age should understand. Arbitrarily designating chronological age to older people is not beneficial, as most people remain independent irrespective of their age, and enjoy good health and quality of life (Neuburger, 2009).

Furthermore, no matter what chronological age a person is, it is still worth treating health problems (Mitchell, cited in Davidson *et al.*, 2013).

My father was, and my mother still is, a unique individual. Both were fiercely independent, and my father did everything in his power to live longer than his parents, who both died at the age of 67. Taking self-responsibility he kept his weight down by watching his diet ('I eat to live, not live to eat'), not smoking and rarely drinking alcohol. He exercised on a regular basis until a hip replacement in his early eighties curtailed these activities. He was the more sociable of my parents and his social networks and friendships endured until his mid-eighties. However, once his mobility decreased and not fully embracing digital technology, he started to neglect his social networks. On the other hand, my mother has always been a 'loner' and seems quite happy with little human interaction. She continues to make few direct demands on anyone caring for her.

In their mid-eighties both my parents became exclusively reliant on their children as they lacked other significant relationships or social networks, and this was the time that my caring responsibilities increased. My father became very demanding as he did not have his friends to turn to and our relationship changed. Viewing having friends as important for all individuals, I encouraged our parents to maintain friendships and despite their lack of energy, or inclination to be proactive in this respect, it would be oversimplistic to attribute this simply to the ageing process. From a selfish point of view as an informal family carer, increased social interaction by my parents would have given me some respite, knowing that they had/have other people to talk to and draw on for support. Overall, the differences between my father and mother in their personalities, relationships and practices whilst advancing in years challenges the idea that all older people are similar by virtue of their age.

The myth of inflexible personality

This suggests that older peoples' personalities change with age, in that they become more inflexible, intolerant and conservative. However, individuals often want to retain choice and control of their decision making. Moreover, they desire clear guidance and support from professionals and especially from family, who are often the first port of call for both accessing support and discussing decisions (Blomgren *et al.*, 2012; Redding *et al.*, 2014).

My father up until his death tried to remain flexible. In his early eighties he adopted two dogs to help a friend out, ignoring the long-term consequences of his actions. My response was to become intolerant and inflexible, labelling my father as selfish, as I would have to look after the dogs if his health deteriorated. With hindsight I should have been more encouraging, since the dogs gave my father unconditional love and the support and company he was missing in later life from friends. This contradicts the often unchallenged assumption that there is no substitute for human touch (Jenkins, 2017).

In the last year of my father's life my parents reluctantly agreed to move from their large detached home, in which they had resided for 50 years, into a small rented bungalow. They coped well with the stress of this huge life transition and the introduction of formal carers and telecare to enable them to reside at home.

I was the one bereft for the loss of my childhood home. This links with Schillmeier and Domenech's (2009) reflections on 'home' and transitions, and on the processes of emotions and introduction of technologies to concepts of dwelling and space, for both older people and their families/carers.

Since my father was terrified of dying, unfortunately he ignored this prospect and did not take up opportunities to put his affairs in order; neither of my parents had wills, funeral plans or made any financial arrangements. When my father was in hospital before he died, a nurse described this as having a 'Blitz mentality', *i.e.* just get on with life and hope the issues go away. This was most challenging to my brother and I, and in the end, we probably limited their choice and control over decision making, by 'swooping in' and taking control. After numerous accidents in his car, as a result of which I expressed the concern that he may injure a child, my father declared 'I don't care if I knock over a child, I need my independence!' This uncharacteristic declaration was more than likely a result of his vascular dementia. However, with the luxury of time and the benefit of hindsight, I should have discussed with him his perceived loss of independence in more detail before I effectively banned him from driving.

The myth of misery

This asserts that because people are older, they are unhappy. Those in the fourth age may feel vulnerable and there is a perception that any criticism of a service will result in its withdrawal. Consequently, they may appear as being unhappy by default (Konno *et al.*, 2012). My father tried to enjoy his life until the end and I suspect the thought of not being as mobile, or as physically able after being hospitalised, precipitated his demise and eventual death. While my father was in hospital for the last time, my mother remained optimistic and positive with my father about his health up until the end. She also seemed to become more independent and caught buses and taxis by herself, for the first time in several years. She did not dwell on the negatives and got on with living.

It was myself and my brother who were miserable and often felt like we were living in 'purgatory', especially during the last month of our father's life. It was a constant battle to keep him in hospital where he was safe; I spent considerable time advocating on his behalf with the medical personnel who wanted to discharge him, as they needed his bed. Our lack of control was challenging, in that we could not know what the future would hold, and we assumed and anticipated the worst. We were the ones experiencing misery. Putting this into context, life beyond our parents still carried on, with all the stresses and pressures of day-to-day family living, professional lives, our own health issues, and our own social and emotional needs. During this period, having friends sit and listen was highly valued, and this is something that my parents were not fortunate enough to experience.

Informal carers for ageing parents are often at breaking point. The demands placed on them are immense and navigating the system and making life-changing decisions is often extremely challenging. As a society we need to establish what is reasonable for families to do and the help they can access to support them as carers. There is currently little appreciation of how much informal care many families are already providing for their ageing relatives. Asking families to do more will not fix

the inherent problems in our health and social care systems. More support needs to be given to those who are carrying enormous amounts of responsibility for ageing relatives (Grünwald *et al.*, [in press](#)) so that stress reduces, positive caring can occur and relationships can remain intact (Tolkacheva *et al.*, [2011](#)).

The myth of rejection and isolation

There are arguments that British society is ageist, uncaring towards and rejects its older people. On the other hand, there may be an expectation that health and social care services should be cost-free. The financial costs attached to these services can manifest in older people feeling rejected, isolated and ultimately stigmatised. This may consequently lead to an unwillingness on the part of the older person to accept those services (Konno *et al.*, [2012](#)). Moreover, feelings of social isolation can occur even in the presence of a large number of other people (*i.e.* in a nursing home), and if we are to address those feelings we need to recognise the importance of social support via relationships with health and care professionals, despite the challenge in terms of the available time that professionals have (Redding *et al.*, [2014](#)).

For many people, social interaction needs to continue, or indeed, increase when we enter the fourth age. However, others like my mother may value solitude and choose to only interact with and have a small number of contacts (Redding *et al.*, [2014](#)). The fourth age is also a time of bereavement and loss, which may reduce older people's support networks; therefore, older people may need to be encouraged and supported to participate and engage (Mitchell, cited in Davidson *et al.*, [2013](#)). Social relationships are as important as a healthy diet and exercise for mental and physical health and successful ageing (Bowling, cited in Davidson *et al.*, [2013](#); Pearce *et al.*, [2019](#)).

My parents have not been isolated during the last five years and have had good relationships with their family and eventually their formal carers. My mother's choice not to have a wide social circle may have helped her since my father's death, in that she seems happy in her own company. She is not isolated in the sense that she has formal carers visiting her four times a day and she enjoys a chat with them all. She shares the experience of many older people in that her carers are numerous, but she has a core team of about eight females so there is some continuity of care. We are all individuals with different personalities: unlike my mother who enjoys solitude, I have consciously made friends throughout my life and nurture and sustain these relationships, and I look forward to maintaining these as I age.

The myth of dependence and unproductivity

This myth perpetuates the belief that because older people are not usually engaged in paid employment, they are not productive members of our society and they are therefore dependent upon others. It could be counter-argued that older people, by using the formal services provided by professional carers, instead of relying upon family and friends, are exerting their own independence and choice. Older people may not choose to give up their independence and still want to be involved in decisions about their lives (Davidson *et al.*, [2013](#)). Essentially, it is the unmet needs

associated with physical or mental ill health, and not necessarily age, which lead to a loss of independence and needing care from others.

There is a constant tension between independence and safety which is often ‘problem focused’ rather than looking at those in the fourth age as individuals (Redding *et al.*, 2014). They are often able to do activities that are important to them, to help maintain a sense of pride, achievement and identity, such as doing the washing-up, and may be disappointed when these everyday tasks are taken over by carers (Redding *et al.*, 2014). There is a need not only to be cared for but cared about when major decisions are made; *e.g.* trusting someone with Lasting Power of Attorney over decisions relating to one’s care and finances (Lloyd, cited in Davidson *et al.*, 2013). Rather than being unproductive, Redding *et al.* (2014) found that most participants in their research referenced the future, putting plans in place for supporting family in their absence, *e.g.* with funeral arrangements.

My parents’ different personalities resulted in my father wanting to experience going out every day and this had a therapeutic effect for him. However, this was not without risks and it compromised our relationship as a result. Van Steenwinkel *et al.* (2017) highlight the importance of freedom of movement and the balance between experiencing freedom and being bound to social (imposed by their children in my parents’ case) and physical (their new home) frameworks. They also challenge the idea of family-like group living (Van Steenwinkel *et al.*, 2017) and indeed my parents’ desires were very different, with my mother wanting to stay at home and my father insisting on her accompanying him every day. Every Monday morning would result in a telephone call to me, with my father irate that my mother would not go out with him for the day. Because of my determination to reduce risks (Chalfont, 2013), I felt the need to constrain my father in his home and reduce his movements, and often any person-centred care ground to a halt.

With hindsight I should have developed more ‘risk-assumed’ activities involving the whole family (Chalfont, 2013). Furthermore, I should have viewed my father’s wanderlust and desire to enjoy his freedom as focused and therapeutic, and ultimately improving his wellbeing (Wigg, 2010). I should have encouraged him to go out safely by incorporating surveillance technologies to monitor his whereabouts, thus increasing his experiences/opportunities and his quality of life and health. This would have challenged both the ‘medicalisation’ of this behaviour, as well as my tendency to underline its riskiness (Wigg, 2010).

With regards to dependence, we all have our own unique experiences, and I am aware that my parents were quite privileged as seniors, in that they had good jobs and subsequent pensions and could afford formal private care. I did involve a social worker initially to ask for help and support with my parents, but my mother’s previous management role in social services made it uncomfortable for her to have social work involvement. Because of this, she became ‘resistant to care’ and cancelled services without my knowledge. When their house became neglected, and my parents started to miss meals and could no longer deal with correspondence, finances or any decisions, my brother and I felt forced to invoke a Lasting Power of Attorney and employ formal carers on their behalf.

Without the help of social services and not knowing where to access good reliable services, this involved endless telephone calls and there were several setbacks

before a reliable service was found. With hindsight, I was not attuned to the adaption that my parents would have to make when formal carers came into their home. I was too engrossed with my own worries regarding their safety and probably 'infantilised' them (Hockey and James, 1993) to protect them. They were, in fact, just told what was happening, with little collaboration or participation involved. Their safety became the main issue at the expense of their choice, which retrospectively could be viewed as oppressive. In circumstances like these there is always the potential for intra-family conflict with decision making. I am aware of how fortunate I was in that I did not have to make any decisions alone and relieved that my brother and I have never argued about any aspect of caring for our parents. My experiences support findings by Romoren (2003) in that the informal care given to older parents by sons is often underestimated.

The myth of physical ill health

This perpetuates the view that old age automatically involves deterioration in physical health and that illness is part of the ageing process. It is recognised that even frail people in their fourth age need 'to get up and moving' (Davidson *et al.*, 2013: 5), as mobility or functionality once lost is hard to recover. Whilst older people recognise the constraints that their health conditions sometimes place on their lives, they often focus on living and are not preoccupied with their health (Redding *et al.*, 2014). Many older people described as 'frail' dislike the term and want to be supported to be as independent as possible. Subsequently, services investing in 'frailty' strategies risk being rejected by the very people they are seeking to support (Redding *et al.*, 2014). Furthermore, there is often a 'risk-averse' attitude among both health and social care professionals and individual's families, which often results in older people being discouraged from participating in activities of daily living (Redding *et al.*, 2014).

Unfortunately, the last five years saw a decline in the health of both of my parents, which involved reduced mobility and increased medication. Antecedent to my father's death, both parents experienced a 'revolving door' into hospital, where they were 'patched up' and returned home. These hospital admissions often coincided with me just about to go on a work trip overseas. After one such episode, a respite residential care admission was sought for both of my parents, although on reflection this was as much about respite for me as it was for my parents. There are various 'landscapes of care' (Milligan and Wiles, 2010: 736) and 'care at a distance' is difficult for all involved. However, during the times I may have been physically distant, I was still closely involved in organising care for my parents, with the added complexities of time differences affecting telephone conversations (Milligan and Wiles, 2010).

The dual stresses of caring for my parents and working overseas may have impacted my own health issues and I was admitted to hospital during this time, and my father asked, 'what will we do if anything happens to you?' My own health needs were ignored until the resulting hospital admission, as I did not have the space to deal with them. The role of carer and my parents' needs took priority, with me eating in the car after work on my way to visit my parents and forgoing exercise. This corroborates the research by Bauer and Soua-Poza (2015), Kelly

and Kenny (2018) and Pinquart and Sörensen (2007). It is so apparent that the physical health of informal carers and those being cared for are entwined in far-reaching ways.

The myth of mental deterioration

This suggests that older people deteriorate mentally and become ‘senile’ (Dixon and Gregory, 1987), and that the presence of mental health problems presents challenges to communication. Mental health problems are often undiagnosed by health-care professionals, and the stigma surrounding these illnesses often makes people reluctant to seek help (Royal College of Nursing, 2018). However, it is important to note that not all people in the fourth age suffer mental health problems. In addition to physical and mental health, personality may be a factor affecting longevity (Davidson *et al.*, 2013).

During the last five years, unfortunately both my parents have suffered some memory loss and my father was diagnosed with vascular dementia. This has caused me some challenges and issues in my role as an informal carer. I have experienced feelings of guilt because there were times when I found it difficult to like being with my father, mainly precipitated by what I regarded as his self-centred and attention-seeking behaviour. However, we have also shared funny times and on both sides a sense of humour (Reilly *et al.*, 2020) and positive mental attitude were vital. Overall, despite my absolute commitment to person-centred care, I often became directive when my parents’ safety was potentially compromised.

The Mental Capacity Act sets out a regime which governs the making of decisions for people who lack mental capacity, based on what is in their best interests (HM Government, 2005: section 4). The key aims are empowerment, protection and support, balanced against physical risk, welfare and happiness, and the patient’s wishes and values. It has been questioned, however, whether the best interests test is ‘fit for purpose’ for vulnerable older people (Szelepet, 2018). Indeed, balancing protection and safety with my father’s wishes and happiness created a huge challenge; a compromise had to be found between the intellectual and the emotional aspects of his care. As an informal carer it is difficult, if not impossible, to reconcile these stresses and the attendant feelings. Over the last five years, I had mourned the loss of my relationship with my father as I knew him. Therefore, I experienced feelings of relief when my father died, feelings which were ultimately tied up with anticipatory and post-bereavement grief and guilt (Aronson, 1990).

Conclusion

The ‘deficit conception of ageing’, which perpetuates the myths above, needs to be abandoned, as stereotypical images of older people in dominant public discourses can intersect with and have an adverse effect on health and social care policies and practices. Moreover, ageing is unequal as class and socio-economic factors impact upon how someone develops during the fourth age. It is evident from this autoethnographical reflective account that what needs to be recognised in social work education and practice are the experiences of carers and the individual characteristics and not the age of a person. Individuality in the fourth age can so easily become

submerged by the pressures facing carers and health and social care systems. Furthermore, the experiences, physical health and emotional impact of caring are often intertwined for both older people and their carers, and this needs acknowledgement. My parents were and are individuals and as an informal carer I have my own story to tell; personal knowledge in social work education is often just as rich as formal knowledge in relaying important messages.

The key issues identified from the dual roles of informal carer and social work educator include problematising the value of expertise based on experience. Reflexivity and critical reflection need to be facilitated in teaching, to relate social work theory, power imbalances and personal experiences to practice. The tensions between freedom and autonomy and the safety and security of my parents and ambivalences of care which I encountered, also need to be questioned and acknowledged as very real concerns when working with those in the fourth age. Individualistic and paternalistic practices need to be avoided and older people need to be not only cared for, but cared about when making decisions. This may involve being less risk averse and carefully discussing, collaborating with and weighing up safety issues *versus* choice, and adapting technology to enable this. Overall, professional education and practice needs to consider the impact of the experiences of the caring role and the personal, cultural, geographical, social and health issues which influence the ageing process. Outcomes for older people when these issues are addressed are more efficient, sustainable and cost-effective (Social Care Institute for Excellence, 2016).

The links between personal caring experiences and relationships and wider social/cultural/professional issues are a useful basis for our own and for the development of others' professional social work practices. My experiences as an informal family carer have forced me to confront the issues of risk, autonomy, communication and grief. In future teaching sessions with student social workers, I will use my own journey, and encourage others to use their own narratives of their lived experiences, to critique some of the stereotypical myths and theories perpetuated in society regarding the fourth age. Carers who have gone some way to resolve these tensions will ultimately provide a better service for those cared for.

Overall, there is a necessity to identify, critique and challenge ill-informed and oppressive language, labels and discourses used to describe people in the fourth age and to explain ageing issues. Social work educators and, indeed, all professionals need to reflect on and challenge the myths of ageing and avoid 'knee-jerk' reactions. I have learned considerably from my informal caring experiences, which will have a positive impact on my teaching and any future practice. By being open, authentic and frank about our experiences, failings and practices (however personally uncomfortable), we can give meaning to issues and encourage others to do the same. It is only by testing and critiquing popular discourses of ageing that we can improve on how we work with those in the fourth age, age successfully ourselves and make life easier for those who may end up meeting our care needs.

Acknowledgments. I am very grateful to Neil Ventress, Dr David Blackwell, Fiona Bridle and Duncan MacInnes for their time, encouragement and generous feedback on drafts of this article.

Conflict of interest. The author declares no conflicts of interest.

Ethical standards. As this is a personal reflective commentary and as my mother has capacity and has always encouraged education, ethical approval was sought and granted by her, to use her experiences for the benefit of learning. Therefore, Northumbria University did not require a submission for ethical approval.

References

- Adams TE, Holman Jones S and Ellis C (2015) *Autoethnography: Understanding Qualitative Research*. New York, NY: Oxford University Press.
- Age UK (2018) *Why Call It Care When Nobody Cares?* London: Age UK.
- Age UK (2019) *Age UK Briefing: Health and Care of Older People in England. The Health and Care Needs of Our Ageing Population*. London: Age UK.
- Anghel R and Ramon S (2009) Service users and carers' involvement in social work education: lessons from an English case study. *European Journal of Social Work* **12**, 185–199.
- Aronson J (1990) Women's perspectives on informal care of the elderly: public ideology and personal experience of giving and receiving care. *Ageing & Society* **10**, 61–84.
- Bauer JM and Souza-Poza A (2015) Impacts of Informal Caregiving on Caregiver Employment, Health and Family. *Journal of Population Ageing* **8**, 113–145.
- Blomgren J, Breeze E, Koskinen S and Martikainen P (2012) Help from spouse and from children among older people with functional limitations: comparison of England and Finland. *Ageing & Society* **32**, 905–933.
- Borland S (2011) Don't sneer at 'frequent flyer' patients: doctors told to stop using common NHS insult. *The Daily Mail*, October 21.
- Buckner L and Yeandle S (2015) *Valuing Carers 2015 – The Rising Value of Carers' Support*. London: Carers UK.
- Butler J (2018) Reflection on emotion in social work. In Mantell A and Scragg T (eds). *Reflective Practice in Social Work*, 5th edn, London: Learning Matters, pp. 39–63.
- Bytheway B (1994) *Ageism*. London: McGraw-Hill Education.
- Bytheway B (1996) Progress report. The experience of later life. *Ageing & Society* **16**, 613–624.
- Bytheway B (2005) Ageism and age categorization. *Journal of Social Issues* **61**, 361–374.
- Calasanti TM (2006) Gender and old age: lessons from spousal carework. In Calasanti TM and Slevin KF (eds). *Age Matters: Realigning Feminist Thinking*. London: Taylor & Francis, pp. 269–294.
- Calasanti TM (2016) Combating ageism: how successful is successful aging? *The Gerontologist* **56**, 1093–1101.
- Calhoun C, Gerteis J, Moody J, Pfaff S and Virk I (2012) *Contemporary Sociological Theory*, 3rd Edn. Chichester, UK: Wiley-Blackwell.
- Carers UK and Age UK (2016) *Walking the Tightrope*. London: Carers UK and Age UK.
- Carersweek.org (2019) *Getting Carers Connected. Research Summary Carers Week 2019*. London: Carersweek.org
- Chalfont G (2013) Beyond risk: the rewards of nature. *Journal of Dementia Care* **21**, 32–34.
- Chang H (2008) *Autoethnography as Method*. Walnut Creek, CA: Left Coast Press.
- Chiu W, Chan AW, Snape E and Redman T (2001) Age stereotypes and discriminatory attitudes towards older workers: an East–West comparison. *Human Relations* **54**, 629–661.
- Commission for Social Care Inspection (2009) *Experts by Experience*. London: Commission for Social Care Inspection.
- Curran D and Chattopadhyay I (2015) Survey on the attitudes of hospital doctors towards the terms 'acopia' and 'social admission' in clinical practice. *Clinical Medicine* **15**, 312.
- Davidson S, Goodwin J and Rossall P (2013) *Improving Later Life. Understanding the Oldest Old*. London: Age UK.
- Demos (2018) *A New Settlement Between Carers and the State: The Carer's Covenant*. London: Demos.
- Department of Health (2002) *Requirements for Social Work Training*. London: Department of Health.
- Dixon J and Gregory L (1987) Ageism. *Action Baseline Winter*, 21–23.
- Doloriert C and Sambrook S (2009) Ethical confessions of the 'I' of autoethnography: the student's dilemma. *Qualitative Research in Organizations and Management: An International Journal* **4**, 27–45.
- Duffy F (2017) A social work perspective on how ageist language, discourses and understandings negatively frame older people and why taking a critical social work stance is essential. *British Journal of Social Work* **47**, 2068–2085.
- Ellis C (2004) *The Ethnographic I: A Methodological Novel About Autoethnography*. Walnut Creek, CA: AltaMira Press.

- Fook J and Askeland GA** (2007) Challenges of critical reflection: nothing ventured, nothing gained. *Social Work Education* **26**, 520–533.
- Grünwald O, Damman M and Henkens K** (in press) Providing informal care next to paid work: explaining care-giving gratification, burden and stress among older workers. *Ageing & Society*. Available online doi:10.1017/S0144686X20000215.
- Hakaka Y and Holmes K** (2017) Film review: Life at the other end: participatory film making, power and the ‘common third’. *Social Work Education* **36**, 217–222.
- Healy K** (2012) *Social Work Methods and Skills: The Essential Foundations of Practice*. Basingstoke, UK: Palgrave Macmillan.
- Hemingway E** (1964) *A Moveable Feast*. New York, NY: Scribners.
- Hepworth M** (2000) *Stories of Ageing*. Buckingham, UK: Open University Press.
- Hickson H** (2011) Critical reflection: reflecting on learning to be reflective. *Reflective Practice* **12**, 829–839.
- Higgs P and Gilleard C** (2020) The ideology of ageism *versus* the social imaginary of the fourth age: two differing approaches to the negative contexts of old age. *Ageing & Society* **40**, 1617–1630.
- HM Government** (2005) *Mental Capacity Act*. Available at www.legislation.gov.uk/ukpga/2005/9/contents.
- Hockey J and James A** (1993) *Growing Up and Growing Old. Ageing and Dependency in the Life Course*. London: Sage.
- Jenkins N** (2017) No substitute for human touch? Towards a critically posthumanist approach to dementia care. *Ageing & Society* **37**, 1484–1498.
- Kelly A and Kenny C** (2018) *Unpaid Care*. Available at <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/POST-PN-0582>.
- Konno R, Kang HS and Makimoto K** (2012) The best evidence for minimizing resistance-to-care during assisted personal care for older adults with dementia in nursing homes: a systematic review. *JBI Library of Systematic Reviews* **10**, 4622–4632.
- Kwan CK and Reupert A** (2019) The relevance of social workers’ personal experiences to their practices. *British Journal of Social Work* **49**, 256–271.
- Lam CM, Wong H and Leung TTF** (2007) An unfinished reflexive journey: social work students’ reflection on their placement experiences. *British Journal of Social Work* **37**, 91–105.
- Latimer JE** (2018) Repelling neoliberal world-making? How the ageing–dementia relation is reassembling the social. *The Sociological Review* **66**, 832–856.
- Levy BR** (2001) Eradication of ageism requires addressing the enemy within. *The Gerontologist* **41**, 578–579.
- Lewis J** (2002) Gender and welfare state change. *European Societies* **4**, 331–357.
- Manzano-Santaella A** (2010) From bed-blocking to delayed discharges: precursors and interpretations of a contested concept. *Health Services Management Research* **23**, 121–127.
- McInnes A** (2004) Meldrew or Methuselah: the mythology of old age. *Generations Review: Journal of the British Society of Gerontology* **14**, 22–24.
- McKie L, Gregory S and Bowlby S** (2002) Shadow times: the temporal and spatial frameworks and experiences of caring and working. *Sociology* **36**, 897–924.
- McLaughlin H** (2009) What’s in a name: ‘client’, ‘patient’, ‘customer’, ‘expert by experience’, ‘service user’ – what’s next? *British Journal of Social Work* **39**, 1101–1117.
- Milligan C and Wiles J** (2010) Landscapes of care. *Progress in Human Geography* **34**, 736–754.
- Minkler M** (1996) Critical perspectives on ageing: new challenges for gerontology. *Ageing & Society* **16**, 467–487.
- Naylor C, Das P, Ross S, Honeyman M, Thompson J and Gilbert H** (2016) *Bringing Together Physical and Mental Health. A New Frontier for Integrated Care*. Available at https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Bringing-together-Kings-Fund-March-2016_1.pdf.
- Neuburger J** (2009) What does it mean to be old? In Cann P and Dean M (eds), *Unequal Ageing: The Untold Story of Exclusion in Old Age*. Bristol, UK: Policy Press, pp. 101–121.
- Office for National Statistics** (2018) *Household Satellite Account, UK: 2015 and 2016*. London: Office for National Statistics.
- Pearce E, Wlodarski R, Machin A and Dunbar RIM** (2019) Exploring the links between dispositions, romantic relationships, support networks and community inclusion in men and women. *PLOS ONE* **14**, e0216210.

- Petrie K and Kirkup J** (2018) *Caring for Carers. The Lives of Family Carers in the UK*. London: Social Market Foundation.
- Pickard L** (2015) A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032. *Ageing & Society* **35**, 96–123.
- Pinquart M and Sörensen S** (2007) Correlates of physical health of informal caregivers: a meta-analysis. *Journals of Gerontology: Psychological Sciences and Social Sciences* **62B**, 126–137.
- Preston-Shoot M** (2007) Whose lives and whose learning? Whose narratives and whose writing? Taking the next research and literature steps with experts by experience. *Evidence and Policy* **3**, 343–359.
- Pursch B and Isden R** (2018) *Behind the Headlines: The Battle to Get Care at Home*. London: Age UK.
- Redding D, Gentry T, Shand J and Stuart L** (2014) *I'm Still Me. A Narrative for Coordinated Support for Older People*. London: National Voices, Age UK and UCL.
- Reilly ST, Harding AJE, Morbey H, Ahmed F, Williamson PR, Swarbrick C, Leroi I, Davies L, Reeves D, Holland F, Hann M and Keady J** (2020) What is important to people with dementia living at home? A set of core outcome items for use in the evaluation of non-pharmacological community-based health and social care interventions. *Age and Ageing* **49**, 664–671.
- Richards R** (2008) Writing the othered self: autoethnography and the problem of objectification in writing about illness and disability. *Qualitative Health Research* **18**, 1717–1728.
- Romoren TI** (2003) The carer careers of son and daughter primary carers of their very old parents in Norway. *Ageing & Society* **23**, 471–485.
- Rowe JW and Kahn RL** (1997) Successful aging. *The Gerontologist* **37**, 433–440.
- Royal College of Nursing** (2018) *Mental Health*. Available at <https://www.rcn.org.uk/clinical-topics/mental-health>.
- Rummery K and Fine M** (2012) Care: a critical review of theory, policy and practice. *Social Policy and Administration* **46**, 321–343.
- Sakellariou S** (2015) Creating in/abilities for eating. *Science, Medicine, and Anthropology*. Available at <http://somatosphere.net/2015/creating-inabilities-for-eating.html/>.
- Schillmeier M and Domenech M** (2009) Care and the art of dwelling: bodies, technologies and home. *Space and Culture* **12**, 288–291.
- Scourfield P** (2010) A critical reflection on the involvement of ‘experts by experience’ in inspections. *British Journal of Social Work* **40**, 1890–1907.
- Sellick MM, Delaney R and Brownlee K** (2002) The deconstruction of professional knowledge: accountability without authority. *Families in Society: The Journal of Contemporary Social Services* **83**, 493–498.
- Sidell M** (1995) *Health in Old Age: Myth, Mystery and Management*. Buckingham, UK: Open University Press.
- Smith J** (2012) The resilient survivor – a student social worker’s journey. *Social Work Education: The International Journal* **33**, 3–14.
- Social Care Institute for Excellence** (2016) *Co-production in social care: What it is and how to do it*. Available online at <https://www.scie.org.uk/publications/guides/guide51/>.
- Starr M and Szebehely M** (2017) Working longer, caring harder – the impact of ‘ageing-in-place’ policies on working carers in the UK and Sweden. *International Journal of Care and Caring* **1**, 115–119.
- Stockwell-Smith G, Kellett U and Moyle W** (2010) Patient and carer perspective: why carers of frail older people are not using available respite services: an Australian study. *Journal of Clinical Nursing* **19**, 2057–2064.
- Szelepet EM** (2018) The Mental Capacity Act 2005 best interests test as applied to the elderly – is it fit for purpose? *Medico-Legal Journal* **86**, 142–146.
- Tierney WG** (1998) Life history’s history: subjects foretold. *Qualitative Inquiry* **4**, 49–70.
- Tolkacheva N, Van Groenou MB, De Boer A and Van Tilburg T** (2011) The impact of informal caregiving networks on adult children’s care-giver burden. *Ageing & Society* **31**, 34–51.
- Tronto J** (2017) There is an alternative: homines curans and the limits of neoliberalism. *International Journal of Care and Caring* **1**, 27–43.
- Twigg J** (2004) The body, gender, and age: feminist insights in social gerontology. *Journal of Aging Studies* **18**, 59–73.
- Van Steenwinkel I, de Casterlé BD and Heylighen A** (2017) How architectural design affords experiences of freedom in residential care for older people. *Journal of Aging Studies* **41**, 84–92.

- White S** (2001) Auto-ethnography as reflexive inquiry: the research act as self-surveillance. In Shaw I and Gould N (eds), *Qualitative Research in Social Work*. London: Sage, pp. 100–115.
- Wigg JM** (2010) Liberating the wanderers: using technology to unlock doors for those living with dementia. *Sociology of Health and Illness* **32**, 288–303.
- Willetts D** (2019) *The Pinch: How the Baby Boomers Stole Their Children's Future – and How They Can Give It Back*. London: Atlantic Books.

Cite this article: McInnes A (2021). Navigating the choppy waters to Nirvana: A critical reflective account of caring for ageing parents in the fourth age. *Ageing & Society* 1–17. <https://doi.org/10.1017/S0144686X20001956>